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ABSTRACT

This packet contains six information pages providing basic answers to questions commonly asked by people involved with individuals who are deaf blind. The first one is on understanding deaf-blindness and addresses what the condition is, its impact on the ability to receive information, how the condition affects caregiver strategies, and what it is like to be deaf-blind. The second information page is on communication for individuals with deaf blindness. This page considers how such individuals communicate, how a caregiver can know which form of communication to use, the importance of a calendar system, the role of trust and bonding, and troubling behavior. The third information page considers behavior interventions for individuals with deaf-blindness. It discusses how deaf blindness and challenging behavior can be related, provision of more information to reduce behavior problems, teaching communication strategies, and the relationship of quality of life and communication/behavior. The fourth information page considers environmental modifications for individuals with deaf-blindness such as the need for special places, specific environmental changes, the importance of consistency and routine, reduction of visual and auditory "clutter," and modification of materials. The fifth information page discusses the importance of and ways to encourage active participation by individuals with deaf blindness. The last page lists six Texas resources for further information. (DB)

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ED 390 202

INFORMATION PAGES:

For People Involved in the Lives of Individuals with Deaf-Blindness

Answers to Questions Commonly Asked by Families, Professionals, and Members of the Community.

1. Understanding Deaf-Blindness
2. Communication for Individuals with Deaf-Blindness
3. Behavior Interventions for Individuals with Deaf-Blindness
4. Environmental Modifications for People with Deaf-Blindness
5. Active Participation for Individuals with Deaf-Blindness
6. Resources for Further Information on Deaf-Blindness

Developed by David Wiley,
Deaf-Blind Outreach, Texas School for the Blind and Visually Impaired

for the Interagency Task Force for Future Services to Deaf-Blind

These information pages provide a very basic answers to questions asked by people who know someone who is deaf-blind. You may find them helpful if you have a family member, neighbor, coworker, client, or customer who has both a vision and a hearing impairment. The information applies to all individuals with deaf-blindness, including those with additional severe disabilities. Of course each individual is unique, so people using these fact sheets will have to apply the information in different ways.

This packet is only the first step in helping you interact with, understand, and support people who are deaf-blind. It will not provide a thorough understanding of deaf-blindness, but it may help you know what questions to ask. The materials, organizations, and people listed in the final information page can provide more in-depth information.

(Revised 5/95)

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Understanding Deaf-Blindness: #1
The combination of vision and hearing impairments.

What is Deaf-Blindness?

Deaf-blindness refers to the combination of both a vision and a hearing impairment. The severity of the vision and hearing loss may vary among individuals who are considered deaf-blind. Most people who are deaf-blind have some functional use of either their vision, hearing, or both. However, even relatively mild sensory impairments require significant special considerations when they occur together.

Deaf-blindness may be a result of genetic abnormalities, illness, pre-mature birth, pre-natal infection, or injury. Some common causes are Usher's Syndrome, Congenital Rubella Syndrome, CMV, and CHARGE Association, among many others. The latter three listed here are often associated with some degree of cognitive impairment and additional disabilities.

There are a significant number of Texans with deaf-blindness. An accurate total for all ages is not available. In 1995 there were 594 students who were registered as deaf-blind in public schools.

Why are special considerations for deaf-blindness important when interacting, developing programs, and arranging the environment?

The combined effects of vision and hearing losses together are much more significant than simply the addition of the effects of blindness and deafness when they occur separately. Vision and hearing are the distance senses--those which allow a person to get information from beyond arms' reach. In many cases adaptations for sensory impairments substitute one distance sense for another: vision for hearing, or hearing for vision. The presence of both these impairments together leaves an individual with no reliable distance senses and requires additional and different accommodations. People with deaf-blindness often have more difficulty communicating; trusting and bonding with others; gaining information incidentally through the environment; moving freely though the environment; and anticipating events.

What impact does deaf-blindness have on the ability to receive information?

It is important to consider the amount of information inaccessible to a person with deaf-blindness. People with no sensory impairments get information through observation. They learn by watching and listening to what happens around them. What they see and hear lets them know what is happening, what to expect, and what other people expect of them. This information is absent or unclear for a person with deaf-blindness. The information most people naturally pick up must be carefully provided in a way that the person who is deaf-blind can understand. Aside from information deliberately supplied by others, someone who is deaf-blind primarily learns things by exploring with touch. Consider everything the average person knows that no one has specifically told him and with which he has no hands on experience. This is all information a person with deaf-blindness may have missed.

How does deaf-blindness affect the strategies employed by caregivers?

Intervention strategies may be used inappropriately when the professionals developing them are unfamiliar with the implications of deaf-blindness. For example, lack of information may be misinterpreted as an inability to understand or cooperate. Special communication strategies, environmental modifications, and the use of consistent routines may help provide this information and make the world less confusing to individuals who are deaf-blind. These strategies may result in an individual being able to independently complete tasks that people may have felt he was unable or unwilling to do.

What it is like to be deaf-blind?

One of the best ways to learn more about deaf-blindness is through simulation. People who provide support to someone who is deaf-blind should try to go through a day completing ordinary tasks without using vision or hearing. Expensive simulators are available, but a blindfold and ear plugs can provide some understanding of the effects of deaf-blindness. By discovering how sensory impairments reduce the information available and cause feelings of isolation and apprehension, concerned people can know more about how to assist someone who is deaf-blind. Simulation also shows how important it is for someone who is deaf-blind to trust the people around him.

Is more information on deaf-blindness available?

To learn more about deaf-blindness and its implications, make use of the resources listed on Information Page #6 in this series. If you do not have this list, contact:

David Wiley; Deaf-Blind Outreach; Texas School for the Blind and Visually Impaired;
1100 W. 45th; Austin, TX 78756; (512)206-9219. (rev. 5/95)

Communication for Individuals with Deaf-Blindness:

#2

How do people who are deaf-blind communicate?

The strategies used by people who are deaf-blind and their communication partners vary widely. Individuals who have both a visual and a hearing impairment often employ unique communication systems. In most cases, these systems can be expanded and shaped so the person develops more communication strategies. Additional strategies may allow the person to understand and be understood by a wider group of communication partners. However, those motivated to meaningfully communicate with a person who is deaf-blind must have flexibility and a willingness to learn the specifics of that person's system.

Everyone uses a variety of forms of communication. In an interaction, any person might speak, gesture, point, hold up an object, draw a diagram, and pat someone on the shoulder. All of these actions contribute to her message. An individual who is deaf-blind may also use a number of different forms of communication. Each person is able to use and understand a different combination of these forms. They might include speech, sign language, tactile sign language, print, braille, pictures, tactile symbols, gestures, objects, physical touch, movement, and signals. There may be some forms of communication a person understands when others use them, even if she does not use them to express herself.

How does a caregiver know which form of communication to use?

The use of consistent routines, touch cues, and repetitive movements by caregivers might be the first way a child who is deaf-blind learns that actions and objects can have meaning. A caregiver who reacts consistently to a child's signals will help the child learn that her actions can influence what other people do. As the child understands this better, caregivers can begin to use objects to represent actions and routines, such as a spoon representing meal time, or a towel representing a bath. When that is understood, more abstract forms such as parts of objects or pictures, and eventually sign language, can be taught and used.

This process of acquiring new communication forms may take years for some people who are deaf-blind, so it should not be rushed. Some people who have severe disabilities in addition to deaf-blindness never learn more abstract communication, and continue to rely on basic forms such as gestures and objects throughout their lives. Communication partners should be careful to speak to the person on her own level by using forms of communication she understands. When trying to teach new language skills, caregivers should not over use more difficult communication forms, as this may only confuse and frustrate the individual who is deaf-blind. New communication forms should always be paired with a familiar form.

Caregivers with no prior knowledge of an individual may be able to find out how she communicates by asking her using speech or sign. If the person doesn't understand, or is unable to respond, information about how to communicate can be learned from others who know the person or past records. If no other information is available, a caregiver should try a variety of messages in several contexts using various communication forms. Observe the individual to see what she appears to understand and take note of the ways she expresses herself.

Why is a calendar important for a person who is deaf-blind?

Because people with deaf-blindness receive less information about what is happening, they have difficulty anticipating events and knowing what to do next. They may be forced to wait patiently until told what to do, with every activity being a surprise. This often results in a person losing her initiative, becoming apprehensive, or resisting. Transitions from one activity to another become difficult. When a person doesn't know what to expect, she experiences no feeling of control about the things that happen.

Calendars are a way to inform a person who is deaf-blind about the events that she should expect. They also provide her with the opportunity to influence those events. Calendars can take many forms, based on the person's level of understanding. A simple shelf where an object is placed to represent the next activity, or an elaborate datebook with activities scheduled for months in advance can both serve as calendars.

A calendar helps a person anticipate what is to come, and remember her agenda. The calendar also provides a way for someone with deaf-blindness to talk about past and future events. These discussions help others understand what the person likes, so she can have more influence over her daily activities and the important issues in her life.

How do trust and bonding affect communication with people who are deaf-blind?

The first communication attempts by many people who are deaf-blind may have been subtle and hard to recognize. As a result, these people may have had early experiences of having their communication attempts ignored or misunderstood. Because communication is difficult, they may have been led through their days without anyone attempting to inform them of what to expect. The message "come with me" might have meant a trip for ice cream or a dental appointment. Consequently, an individual who is deaf-blind often may become distrustful of communication partners. This problem continues when large numbers of professionals work briefly with the individual, having no opportunity to learn her unique communication strategies. These factors contribute to further limiting the person's skills and motivation to communicate. To overcome this, individuals with deaf-blindness need an opportunity to form consistent trusting relationships with attentive communication partners.

How does communication relate to troubling behavior?

For individuals who are deaf-blind, there is a link between communication and challenging behaviors such as self-abuse and aggression. These behaviors may have begun as the most reliable way for a person with deaf-blindness to get her point across. Such behaviors might also be expected expressions of frustration at not being able to call upon reliable communication when needs are not being met. The problem may also stem from anxiety caused by confusion over what is happening and what is to be expected. Most often caregivers can best approach troubling behaviors by treating them as communication attempts, and reduce them by teaching alternative communication strategies.

Providing predictable routines and more information about what to anticipate often reduces anxiety and associated behavior problems. Teaching appropriate ways to seek assistance, make requests, and indicate rejection also helps. As the person successfully uses these strategies, she can decrease reliance on inappropriate ways to communicate. (rev. 2/95)

Behavior Interventions for Individuals with Deaf-Blindness

#3

How are a person's deaf-blindness and challenging behavior be related?

Troubling behavior is often the result of a person's impaired ability to interact with the world. Some individuals who are deaf-blind may develop behaviors such as uncooperativeness, aggression, or self abuse, in trying to make sense of confusing situations they don't know how to communicate about or change. These behaviors might be ways for a person to cope with unpredictable events and situations. They may be effective strategies a person has learned to use when other, more desirable ways to communicate aren't developed. The behavior may be a response to situations which a person find unacceptable and over which she has very little control. In situations such as these, behavior problems may relate directly to deaf-blindness and associated problems in gathering information and communicating. Effective behavioral change will result from efforts to understand and respond to the cause of a behavior, not just the behavior itself.

How can providing more information reduce behavior problems?

When someone gets incomplete or inaccurate information about the world, events in her life may seem like a continuous series of surprises. An individual who is deaf-blind misses significant information about what is happening to and around her. As a result, she can easily begin to feel isolated, frustrated, threatened, or confused. Some aggressive behaviors may be an effort by the individual to protect herself when she is unsure of the situation. Some self-abusive behaviors may be expected expressions of anxiety or frustration. Actions that may be attributed to a lack of cooperation may instead be due to incomplete information about what is expected and why. When caregivers develop strategies for giving more meaningful information about the world to a person who is deaf-blind, troubling behaviors related to these motavations should decrease.

Introducing structure, routine, and predictability into the person's life is one way to supply this information. Predictable routines and familiar activities help people know what to expect. Using consistent communication strategies based on the ability of the person to understand is also important. Supporting communication by using concrete communication forms such as objects, pictures, tactiles symbols, or calendars also reinforces the person's expectations. Providing information using more than one communication form makes messages more clear and understandable. These strategies help a person with deaf-blindness know what to anticipate. By informing a person what to anticipate, anxiety and behavior problems will often decrease as more trust is developed.

How can teaching communication strategies reduce behavior problems?

Some troubling behaviors may be effective strategies a person has learned to communicate things she has no other way to say. This behavior may have begun as the most reliable way for a person to make changes occur when she was unhappy. The person may not know another way to say that she needs something, that she doesn't like something, that she is tired, or that she doesn't feel well. Often the best approach to reducing troubling behaviors is to treat them as communication attempts, and teach alternative strategies for expressing these ideas.

A person who is deaf-blind can be taught more appropriate communication as an alternative to troubling behavior. As the person learns to appropriately seek assistance, make requests, and indicate rejection, she can decrease reliance on more inappropriate ways to communicate. These communication strategies can assist the person in making and expressing choices, enabling the person have a greater sence of control about the activities of her life.

How does quality of life relate to communication and behavior?

People sometimes become depressed, frustrated, or angry when they are not satisfied with their lifestyles. They feel these emotions, for instance, when they are troubled about problems with their homes, interpersonal relationships, jobs, or health. Such feelings may also accompany loneliness, loss of a loved one, or lack of enjoyment in someone's life. Often these feelings are often difficult to express even for people without communication problems. When people with deaf-blindness have no strategies to discuss abstract issues, they may find it impossible to clearly express what they think is wrong in their lives, and how it affects the way they feel. As a result, the appearance of behaviors like biting or hitting may be the only way others find out they are unhappy.

For example, a person with deaf-blindness may communicate about the pain of a middle ear infection by banging his head. He may spit out food to communicate frustration at having little or no control over what he is eating. He may bite an adult in situations he sees as unfair. Children with multiple disabilities are more likely than most to have physical problems like poor digestion, disturbed sleep, and chronic pain. They are less likely to have friendships, control, and access to their favorite things. All of this influences the way they respond to people and daily activities.

If a person with deaf-blindness is behaving in troubling ways, it is important that those who care about her examine and work to improve the quality of her life. People want to be physically comfortable, safe, and secure. They want to be surrounded by people they like. They want to know there are people and things they can trust. They want to do a variety of meaningful and enjoyable things, and have influence over what happens in their lives. Caregivers should consider how this person feels about the circumstances of her own life, and not how the caregiver thinks she ought to feel. Every person decides for herself what is important, what brings joy, and what causes unhappiness. Helping people have what they consider to be safe, comfortable, and satisfying lifestyles is essential for reducung problem behaviors related to negative feelings about quality of life. (rev. 5/95)

Environmental Modifications for Individuals with Deaf-Blindness: #4

Do people who are deaf-blind need special places?

People with deaf-blindness do not need separate and very different environments in which to live, work, and enjoy themselves. They generally share the same homes, workplaces, and recreational facilities with their neighbors and friends who are sighted and hearing. However, there are some simple modifications for any environment that can help a person who is deaf-blind to be more comfortable and independent. These modifications are fair and reasonable accommodations to make spaces, objects, and information more accessible, as well as providing a greater sense of security and reducing frustration.

How can the environment be modified to make things easier for someone who is deaf-blind?

Simplifying the environment is a good first step to making it more accessible for someone who is deaf-blind. Reducing clutter on the floor, tables, countertops, and in drawers makes the environment much easier to understand. People who have deaf-blindness often have more difficulty or need additional time in finding their way, or locating things. A cluttered environment adds to the problem. For example, if the silverware drawer also includes extra miscellaneous items, it is much more difficult for someone who is deaf-blind to locate a fork. A room that is totally full and disorderly is very difficult to walk though.

Keeping clear routes through any space is important. Individuals who are deaf-blind find it easiest to get from one place to another by following large even surfaces such as walls, counters, or railings. Caregivers should help the person who is deaf-blind discover the best route to move toward regular destinations. They should then remove potential obstacles, help the person become familiar and comfortable with each route, and make sure the paths stay clear.

Placing related items near one another also makes activities simpler. For instance, storing the bread beside the toaster makes a quick breakfast far less complicated. Placing all necessary materials on one shelf beside the work station improves efficiency and independence on the job. Materials should also be stored consistently. An individual with deaf-blindness is much more independent when items can always be found in the same place.

Why are consistency and routine in the environment so important?

People with dual sensory impairments have difficulty receiving information about the environment around them from a distance. Changes that might seem inconsequential to someone with no sensory impairments can make things confusing and threatening to someone who is unable to easily detect them. This often reduces a person's ability to independently move through rooms and find materials, increasing the need for assistance during otherwise simple activities.

It is extremely important that changes in the environment be kept to a minimum, and that any changes that are made be shown and explained to the person who is deaf-blind. Obviously,

rearranging furniture can make spaces totally confusing. But it might be equally confusing to add a coat rack, or hang a picture on a wall that someone routinely follows out of a room. Even floor coverings are used as cues to help recognize and locate areas in an environment. Changing the carpet or tile, or resurfacing the driveway should be done with this in mind. Changes that can't be avoided should be shown and explained to a person who is deaf-blind.

Furthermore, adding new hanging plants, shelves on the wall, or throw rugs can result in a serious safety risk. In addition to injury, surprising new features in the environment may result in making a person who is deaf-blind feel less secure about moving through the environment independently. Each time someone trips over a new magazine rack, or unexpectedly encounters a new clothes line, he may become less willing to move about without assistance.

Why is the way things look and sound important?

It is equally important to reduce visual and auditory "clutter", so a person who is deaf-blind can make better use of any vision and hearing she may have. People with sensory impairments may have difficulty separating important visual and auditory cues from the background. For example, if someone using sign language is wearing a shirt with a colorful and busy pattern, his signs will be much more difficult to see. The same problem may be present with patterned wallpaper or curtains. Backgrounds covered with numerous objects or pictures may be visually confusing. Simplifying visual backgrounds and removing unneeded materials helps people with low vision find and concentrate on what needs to be viewed.

Another factor to consider for someone with low vision is lighting. Low light and shadows may make seeing things very difficult. Bright glares may cause similar visual difficulties. Creating environments that have good light without glare is a good start, but some experimentation may be necessary to find the ideal lighting for each individual.

When someone relies on auditory cues, but is hearing impaired, background noise can be a problem. Reducing noise or relocating sources of noise can help. For instance, a noisy fan can be placed on the other side of the room from a person's work station or dining area. When noise sources can not be changed, the environment might be engineered so the person who is hearing impaired is less affected by them. An example might be letting a person move to a bedroom farther away from the central air conditioner.

What modified materials would be helpful?

Items in the environment should be modified based on individual need, rather than general rules. Individuals who can not hear, but have a functional use of vision may find it useful to have fire alarms and door bells wired to flashing lights. Those who are using their vision might also find it helpful for spaces and materials to have clearly contrasting colors and well defined borders. Those who are unable to see, might take advantage of textured surfaces to identify locations and materials. Pens that make raised lines can be used to mark items like washer and dryer dials, to make them easier to use independently. There are many adaptive aids and devices that might help. The resources listed on page #6 can provide further information.

(rev. 2/95)

Active Participation for Individuals with Deaf-Blindness

#5

What can a person with deaf-blindness do?

Of course this question has as many answers as there are people who are deaf-blind. Every person with deaf-blindness has his own skills and interests. There are no activities that are particularly suited for someone who is deaf-blind. Supporting a person to participate in a variety of meaningful, productive, and interesting activities begins by assessing and utilizing: the abilities and preferences of the person; the routines and activities found in the environments the person encounters; and the needs and interests of the people with whom the person regularly interacts.

Some people with deaf-blindness learn to complete most tasks independently. Others, especially those with additional disabilities, need varying amounts of assistance in order to participate in activities. Even if a person does not have the skills to complete a task or activity in its entirety, he may be able to complete a portion or step of the activity and team with someone else who can complete the other steps. This is called partial participation. An example or partial participation might be someone who can not cook a meal, but can toss the salad or slice the bread. Some people may need physical assistance to complete any portion of an activity. This is called co-active participation. Support through partial and co-active participation allows a person to engage in a wide variety of activities, even if he is not independent.

Why is active participation so important for helping someone with deaf-blindness learn?

When a young child has deaf-blindness, he is less motavated to explore the world. He does not perceive all the environmental cues which lead people to become curious about objects and places around them. Consequently, he may learn fewer lessons about the properties of objects and space. Passive stimulation does not develop a person's concepts and capabilities like active participation in learning. Caregivers should provide safe, accessable, and consistent places for a child to spend some time actively exploring and learning these basic concepts. This will provide a better foundation as the child gets older and starts to learn skills and participate in activities.

People who are deaf-blind learn by doing. Most people learn better when they have an opportunity to learn by experience, but for someone with deaf-blindness experience is a necessity. The use of observation and modeling are not effective teaching strategies when the learner has sensory impairments. Watching a friend or classmate participate in an activity may not be an effective way to learn even if a visually impaired person can functionally use his vision in some circumstances. Learning new information visually is much more complicated than recognizing familiar situations. Furthermore, because communication is often a weakness for people who are deaf-blind, explanation using formal language is not a very effective teaching strategy. Words and signs are not meaningful unless an individual associates them with experiences they have had. Lessons should be experienially based.

Wouldn't a person with deaf-blindness be happier if other people took care of him?

Everyone needs the opportunity to feel good about himself and to make contributions to the world around him. Everyone enjoys the feeling of being competent and accomplishing something. People who are deaf-blind are often excluded from these opportunities. It is important the these individuals learn skills in which they feel confident, and that they have a chance to use these skills to gain a sense of belongingness and respect from the people with whom they interact. Such opportunities to make meaningful contributions are are important, even if a person requires adaptations and support to participate.

What if the person objects when asked to participate?

Routines are very important to everyone. Because people who are deaf-blind receive less information about the world around them, routines take on even greater significance. If a person has not been allowed or encouraged to participate in activities in the past, his routine is to stay uninvolved. Non-participation can become a habit, just like a cup of coffee in the morning or an evening walk. Any time these routines are disrupted, it is natural to feel a sense of resistance.

A fuller activity schedule is often rejected be someone who has not had the opportunity to participate very often. New chores may result in troubling behavior for these individuals.

Shouldn't everyone have free time?

Everyone needs a chance to recharge their batteries by resting and participating in enjoyable pastimes. Most people have a repertoire of activities they look forward to doing, and are anxious for a chance when they are free to do them. However, many people who are deaf-blind do not have self-directed activities they can readily call upon when presented with free time.

(rev. 2/95)

Resources for Further Information on Deaf-Blindness

#6

To gain more skill and knowledge about deaf-blindness, you may contact:

The Interagency Task Force for Future Services to Deaf-Blind has representatives from the organizations list below, as well as: Texas Deaf-Blind Association; Texas Department of Health; Texas Commission for the Deaf and Hearing Impaired; Texas Education Agency; and Texas Department of Human Services. The Task Force can be contacted in care of the Texas Commission for the Blind or Deaf-Blind Multihandicapped Association of Texas at the addresses listed below.

The following Task Force representatives provide services, training, information and referral directly related to persons with deaf-blindness:

Deaf-Blind Outreach Texas School for the Blind and Visually Impaired 1100 W. 45th Street Austin, TX 78756 (512) 454-8631 x103	Training for professionals and families involved with school-aged individuals who are deaf-blind, 0-22 years. Workshops, on-site consultation, information and referral services. Mailing list for newsletter and workshop announcements.
Deaf-Blind Services Texas Commission for the Blind 4800 N. Lamar Austin, TX 78756 (512) 459-2575	Training, support, and information on employment and independent living issues for deaf-blind adults. Information and support for families of children who are deaf-blind. Apartment living program.
Deaf-Blind Multihandicapped Services Texas Rehabilitation Commission 4900 N. Lamar Austin, TX 78751 (512) 483-4185	Residential support and an array of services offered through Medicaid waiver dedicated to individuals who are deaf-blind and multiply disabled, age 18 and over. Group homes and in-home support.
Regional Representative Helen Keller National Center 4455 LBJ Freeway, LB #3 Suite 517 Dallas, TX 75244 (214)490-9677	Information, referral, and training for adult service agencies, families, and individuals who are deaf-blind.
The Deaf-Blind Multihandicapped Assn. of Texas 815 High School Dr. Seagoville, TX 75159 (214)287-1904	Family support, advocacy, training, information, and referral for all persons interested in issues related to deaf-blindness.
Physical Management Division Tex. Dept. of Mental Health & Mental Retardation P.O. Box 12688 Austin, TX 78751	Training and support for professionals and staff working with individuals who are deaf-blind being served by TDMHMR and Community MHMR Centers.